

Between delivering chronic care and answering patients' burdens: Understanding HIV specialist nurses' experiences in the age of treatment

Maarten Bedert¹  | Kevin Moody¹ | Pythia Nieuwkerk² | Natasja van Holten³ | John de Wit⁴ | Marc van der Valk^{1,5}

¹Division of Infectious Diseases, Amsterdam Infection and Immunity Institute, Amsterdam University Medical Centers, University of Amsterdam, Amsterdam, The Netherlands

²Department of Medical Psychology, Amsterdam Public Health Research Institute, Amsterdam University Medical Centers, location AMC, University of Amsterdam, Amsterdam, The Netherlands

³Department of Infectious Diseases, Leiden University Medical Center, Leiden, The Netherlands

⁴Department of Interdisciplinary Social Science, Utrecht University, Utrecht, The Netherlands

⁵HIV Monitoring Foundation, Amsterdam, The Netherlands

Correspondence

Maarten Bedert, Division of Infectious Diseases, Amsterdam Infection and Immunity Institute, Amsterdam University Medical Centers, University of Amsterdam, Amsterdam, The Netherlands.
Email: m.r.d.bedert@amsterdamumc.nl

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Abstract

Aim(s): To understand the experiences of HIV nurses in the context of ambivalence between biomedical treatment advancements and the continuing burden for people living with HIV and negative representations of HIV.

Design: An interpretative phenomenological study was conducted using in-depth interviews.

Methods: Twenty-one interviews with nurses were conducted between November 2021 and March 2022. A thematic analysis was performed.

Results: Six themes related to the nurses' experiences emerged. Despite effective treatment for most people with HIV, nurses identify patient populations that require additional care. Nurses are flexible in making extra appointments to accommodate complex issues in these patients. Nurses develop a unique relationship with their patients based on trust and empathy, linked to patient's experiences with stigma and discrimination for people with HIV. Nurses perceive their tasks as becoming increasingly complex. There is explicit awareness about the changes in HIV care from acute to chronic care and how this affects nurses' tasks. Nurses continue to differentiate HIV from other chronic conditions.

Conclusion: Biomedical advancements change the organization of HIV care while public health concerns remain and patient population has particular needs due to negative social representations of HIV. Nurses navigate these issues in their everyday care.

Implications for the Profession and/or Patient Care: A potential re-evaluation of the role of nurses in providing chronic HIV care.

Impact: Our study addresses the roles of HIV nurses as care is shifting towards chronic care models. The unique relationship between nurses and patients is key in understanding the importance of nurses in the care trajectory. These findings impact the institutional role of nurses in HIV treatment centres and the institutional organization of HIV care.

Report Method: The COREQ guideline was used.

Patient or Public Contribution: Amsterdam UMC (AMC) staff, the national organization of HIV Nurses and patient organizations contributed to the study design.

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KEYWORDS

change, chronic care, HIV, nurse–patient relationship, nursing practice, patient-centred care, specialist care

1 | INTRODUCTION

The introduction of effective anti-retroviral therapy (ART) for people with HIV (PWH) in the second half of the 1990s has caused important shifts in both the discourse surrounding HIV and attitudes to care. HIV is now framed and described as a chronic, manageable condition rather than an acute or fatal condition (Beaudin & Chambre, 1996; Siegel & Lekas, 2002). For most patients in continuous routine chronic care, their HIV viral load remains suppressed and undetectable and therefore they are unable to transmit the virus (Rodger et al., 2019). As a result of these biomedical developments, life expectancy of PWH has increased significantly and nearly equals that of people without HIV (Marcus et al., 2020). This picture of HIV as a manageable condition has inspired calls for its ‘normalization’, suggesting the routinization and integration of HIV care and health services into existing services, such as the general practitioner, diminishing the framing of HIV response as a crisis (Mattes, 2022) and shifting funding into existing public health budgets, as opposed to specialized budgets for HIV.

At the same time, PWH are still more likely than the general population to experience comorbidities (van Sighem et al., 2021), mental health issues like depression or social isolation (Orlando et al., 2006), stigma and discrimination (Stutterheim et al., 2017), and an overall worse quality of life (Engelhard et al., 2018). PWH continue to experience significant immediate and long-term burden of disease (van Bilsen et al., 2020) and people without HIV are likely to over-estimate what it means to live with HIV (Zimmermann et al., 2021). From a public health perspective, structural factors and social inequities contribute to late diagnosis (Bedert et al., 2021). In the context of care, social representations of HIV continue to influence the ability of new health workers to provide adequate care for PWH for the worse (Persson et al., 2014).

Against this ambivalent background of biomedical advancement and changes in the organization of care on the one hand and continued experience of burden on the other hand, we set out to understand the experiences of HIV nurses in the Netherlands in providing HIV care, and how they understand and perform their tasks in the age of successful chronic treatment.

2 | BACKGROUND

Biomedical developments have driven major shifts in the organization of HIV care. Over time, three main eras and types of HIV care can be discerned. First, before 1996 and pre ART, treatment options were limited and care was centred around palliative end-of-life care. Second, the availability of effective treatment since 1996 has shifted the focus of care to more bio-technical interventions based

on the suppression of viral loads and the decision to initiate treatment, ensure adherence and manage side effects for patients. Third, since the early 2000s, ART side effects have become more easily managed and treatment immediately following diagnosis has become the norm. This latter phase shifted the focus towards chronic care models that put more emphasis on patient-centred care and on quality of life in light of long-term treatment (Chu & Selwyn, 2011). Policy makers and health professionals have called to move “beyond viral suppression” (Zeluf-Andersson et al., 2019) in the way care is organized. Value-based health care for HIV has become an important theme (Popping et al., 2021), as has the incorporation of patient reported outcome measures (PROs), to increase patient engagement and shared decision making (Kjær et al., 2018), differentiated service delivery (Roy et al., 2019) and increasingly integrated care (Duffy et al., 2017). These calls from inside the clinic are further supported by similar calls from within the patient community as formulated in a recent manifesto (EATG, 2022). An issue that remains under-explored, however, is how this discourse informs the everyday experience and practices of nurses.

Health system analysts have pointed to how chronic conditions require not only management and follow up over a period of years but are also increasingly complex and require coordinated efforts from diverse medical and non-medical professionals. This systemic change is taking place particularly, but not exclusively, in high resource settings where care is presumed to be readily available and affordable for those who need it (McGrath et al., 2014). Patient-centred care has become an important principle in chronic care models. The main characteristics of patient-centred care have been identified in the seminal works of Gerteis and colleagues in the early 1990s (Gerteis et al., 1993) who identified seven themes related to patient-centred care: respect for patients; values, preferences; co-ordination and integration of care; information, communication and education; physical comfort; emotional support involvement of family and friends; transition and continuity. The field of nursing studies has identified its own framework for patient-centred care. The work of McCormack and McCance (2006) incorporate the following domains: the patient experience is central, their expression of beliefs and values needs to be respected, they need to share in decision-making and they deserve effective communication and an integrated approach to care. Despite the presumed central role of nurses in chronic care models, little is known about the actual experiences they have with patients and as part of health care institutions. Overall, a knowledge gap remains with regard to the experiences of nurses since the introduction of effective antiretroviral treatment. No reviews have addressed this topic and most research covers attitudes of nurses towards HIV or patient experiences of receiving care. In the Netherlands, no research has been conducted on the experience of HIV nurses either (Frain, 2017; Hekkink et al., 2005;

Hodgson, 2006; Kyrou et al., 2021; Stutterheim et al., 2014). We set out to explore how nurses delivering HIV care experience everyday practices in the context of increasingly complex approaches arising due to the transition into chronic care models that favour quality of life for patients beyond biomedical markers.

In the Netherlands, about 21,500 people are diagnosed with HIV (van Sighem et al., 2022). All people with HIV receive care in one of the 24 government-accredited specialized HIV treatment centres. PWH are monitored by a treatment team consisting of a medical specialist and an HIV nurse. Routine HIV care entails 6-monthly visits to the treatment centre. Depending on the setup at the clinic, PWH either meet with their doctor and nurse during a consultation or alternate between them if the nurse conducts independent consultations. Overall, patients are regularly seen by one of the 86 HIV nurses in the country. Of those, about half are specially trained registered nurses working in the HIV treatment centres, whereas the other half are nurse practitioners (MSc advanced nursing practice). The main difference between both types of nurses is that a nurse practitioner can have independent, unsupervised, consultations with a patient and can independently prescribe medication. The introduction of HIV nurses goes back to the early days of the HIV epidemic in the Netherlands and was established through community efforts following the first documented case of HIV at the Amsterdam Medical Center in Amsterdam in 1982 (Mooij, 2004; Prummel et al., 1983). Today, nurses are often part of complex interdisciplinary treatment teams. Depending on resources of individual treatment centres and the specific needs of the patient population, other services might be available like a social worker, an in-house mental health specialist or a peer counsellor.

3 | THE STUDY

3.1 | Aim/s, research question

The aim of this study is to gain insight into the experiences of HIV nurses in their everyday practice and the process of meaning making in providing long-term chronic care to their patients in the Netherlands. We frame these experiences against the ambivalence between the biomedical optimism, for instance through advocating for chronic care models, and continuing experience of burden among PWH and negative social representations of HIV, warranting a tailored approach towards patients and care.

4 | METHODS/METHODOLOGY

4.1 | Design

This study was designed as an exploratory, phenomenological, qualitative study using in-depth interviews. We adopt an interpretive phenomenological design as we are seeking to capture the ways in which nurses make sense of their care practices.

4.2 | Theoretical framework

Phenomenology's focus is the study of lived experiences of study participants. Interpretative phenomenological analysis (IPA) relies on hermeneutics and takes into account both the subjective experience of participants of a particular phenomenon and the prior experiences and positionality of the researcher as constitutive of the analysis (Smith & Osborn, 2015). It is an approach that is used to explore topics about which little is known or that are sensitive like HIV or sexuality (Flowers et al., 2011). The in-depth focus on personal experience often generates new insights. IPA entails a constant moving back and forward between ways of thinking about data (Smith et al., 1997). Precisely because it is highly contextual and reflexive, IPA often informs theory and policy formation, not in the least in health care.

4.3 | Study setting and recruitment

We used purposeful sampling methods, well suited for IPA with its focus on the particular among a relatively small group (Smith & Osborn, 2015), to achieve maximum variation and diversity among HIV nurses who work in treatment centres in the Netherlands. We aimed for variation in terms of years of experience, size of the treatment centre and geographical location. Potential participants were informed about the study through the network of the professional organization of HIV nurses. When nurses expressed interest in participating, they were subsequently sent an email containing the study protocol and detailed participant information. Upon confirmation of participation, concrete arrangements were made for a personal, telephone or online video interview. Participation was voluntary and based on informed consent. Participants could withdraw or stop at any time.

4.4 | Inclusion and/or exclusion criteria

Inclusion criterion for our study was working as an HIV nurse. HIV nurses work exclusively in one of the 24 accredited treatment centres and provide HIV care, have completed an HIV masterclass and passed a practical course as prescribed by the national association of HIV nurses.

4.5 | Data collection

We developed an initial interview guide based on literature research, informal conversations with nurses and limited ethnographic research by MB (who conducted the interviews) at the HIV clinic of the Amsterdam University Medical Centers (UMC), Location AMC. The interview guide was refined based on four interviews with HIV nurses from diverse HIV treatment centres. These four interviews were not audio recorded; detailed written notes were made.

The interview guide aimed at introducing key themes to facilitate an inductive analysis. It covered basic demographics like personal and professional background, personal understanding of the job description, description of the interactions with patients and other professional staff, detailing their relationship with patients, perceived changes in HIV care over time and prospects towards the future of HIV care.

Individual interviews with HIV nurses were conducted over a period of 5 months, between November 2021 and March 2022. Interviews were conducted over the telephone ($n=17$), online via Teams ($n=2$) or in person ($n=2$). All interviews took place during working hours. Interviews lasted on average 45 min (range: 28–59 min). Interviews were conducted by MB, a male researcher with a background in social anthropology and prior research experience on HIV late diagnosis. Three participants were acquainted with the researcher through his involvement in a project regarding peer support for people with HIV.

4.6 | Data analysis

All interviews were audio recorded and transcribed verbatim. Data were analysed using inductive thematic content analysis based on open and axial coding (Schreier, 2012) supported by MaxQDA software (VERBI, 2021). Initial analysis was conducted simultaneously with the interviews. Inclusion of participants continued until thematic saturation was reached (Sandelowski, 1995).

4.7 | Ethical considerations

This study was considered exempt by the medical ethical approval committee from the Amsterdam UMC as the Dutch law regarding research with human participants (WMO) did not apply (reference W21_428 # 21.476).

4.8 | Rigour and reflexivity

Findings were discussed among members of the research team, consisting of a social anthropologist, a medical specialist in internal medicine, a clinical psychologist and an implementation scientist on the quality of care. Peer debriefing was conducted with two HIV nurses who were not interviewed as part of the study. All interviews were initially coded by the first author of the study but discussed in detail among the members of the research group.

5 | RESULTS

5.1 | Characteristics of participants

Twenty-one nurses (26% of the total population of HIV nurses in the Netherlands) from 21 of the 24 treatment centres in the Netherlands participated in our study. Participants had an average

working experience at an HIV treatment centre of 15 years (range: 3–30 years). Five participants were male (23%), and 16 female (76%). Of all participants, 9 were HIV registered nurses (a general nursing degree), while 11 were nurses practitioners (an advanced nursing degree) and one was a nurse practitioner in training. One worked in a small treatment centre (≤ 400 PWH in care), 4 in medium size centres (400–700 PWH in care) and 16 in large size centres (≥ 700 PWH in care). 11 nurses worked in treatment centres in the conurbation of the Western Netherlands, whereas 10 worked in the provinces.

5.2 | Findings

Based on the interviews, we identified six themes related to nurses' experiences of providing care. The first three themes are relational in nature. First, nurses identified specific patient groups that require more attention and more care. Second, nurses organize consultations to accommodate patient needs. Third, nurses cultivated a particular relationship with their patients based around the exceptional status of HIV in the social imagination. The second three themes are conceptual in nature. First, nurses identified the increasing complexity of their tasks in providing appropriate care. Second, they reflected on changes that have occurred in how care is designed and organized in line with biomedical developments. Third, nurses ascribed particularities to HIV care in comparison to other chronic conditions.

5.2.1 | Patient populations with additional care needs

Despite effective treatment and regular care, nurses identified specific patient populations that require additional attention and diverging approaches to treatment based on their background, experiences and needs. Nurses distinguished between men who have sex with men (MSM), heterosexual men and women. They additionally distinguished Dutch-born patients from people with a migration background. Nurses associated MSM as being more familiar with HIV, having their own network and requiring little extra care or support, both clinical and extra-clinical: "it is my experience that MSM know how to find each other and, if they can't do that, are able and willing to turn to existing resources [within the system]" (19 years, registered nurse, large centre).

Nurses expressed that heterosexual men and women, and people with a migration background, experience a higher burden of living with HIV. They were considered to have more difficulty with accepting their HIV diagnosis, disclose less frequently, experience more stigma and loneliness, face more challenges in building a community or were generally more vulnerable. Despite good clinical outcomes, nurses felt they had a larger responsibility and commitment towards these patients: "for some, it is so difficult; nobody knows about [their HIV]. That means I am the only one they can disclose their HIV to, and talk openly about it" (9 years, registered nurse, small centre).

This additional concern was not limited to gender, sexual orientation or migration background, but also extended to regional differences within the Netherlands. Nurses working outside of the major cities thought they needed a different approach to treat their patients: “Amsterdam is very different from the provinces. Each time I go to a meeting and hear how GPs do things in Amsterdam; I think: ‘this is impossible [here]’. Our GPs have maybe one HIV patient in care. They call us if the patient has a cough. [I think] ‘does this have [anything] to do with HIV?’. That is a totally different reality.” (15 years, nurse practitioner, large centre).

5.2.2 | Planning of additional consults

Nurses expressed that chronic care does not translate into routinization for all patients. Patients who have entered chronic routine care and whose HIV viral load is undetectable must visit the outpatient clinic twice a year; nurses reported that appointments vary both in time and in interval. Regular consults varied between 20 and 30 min. The very first consultation with new patients, having received a new diagnosis or having transferred from another treatment centre or having just entered care in the Netherlands, was perceived as a cathartic and pivotal moment that required more time and a broader scope. For those patients, double appointments were arranged: “For the first conversation, we have 1 h with our patients [...]. You want to get to know the patient [and] be able to build rapport and a relationship” (4 years, nurse practitioner in training, large centre).

Several nurses indicated that they have some freedom and flexibility to plan consultations depending on the needs of the patients: “Yes, [30-min consultations] was a conscious choice. It gives us room to ask more questions, to address difficult topics. If the consultation is shorter, you might not address difficult issues because there would be no time to properly address them” (16 years, registered nurse, large centre).

Additionally, while 6-monthly visits are the norm, nurses indicated that exceptions are often made and additional visits are scheduled: “If our day is not fully planned, [...] we can always plan an extra appointment. [...] But again, this is for patients who really need it” (9 years, registered nurse, small centre). Another reason to plan extra consultations comes from the nurses themselves and was linked to the public health concern associated with HIV. For instance, they allowed patients with vague complaints that are not necessarily HIV related to come in anyway: “if it is somebody who often does not show up for appointments, we take the opportunity to see them: ‘yes, come to us.’ And some patients do not have a GP, so we also allow them to come” (11 years, nurse practitioner, large centre).

5.2.3 | Unique relationship between the nurse and the patient

Nurses across the board elaborated on the unique relationship they developed with their patients. They consider the depth of this

relationship to be a precursor to delivering good care. Trust is a key factor that determined this relationship: “What is significant is that, as a nurse, you become the primary contact but also the confidant of the patient. Last week we had somebody who was desperate and didn't know who to turn to anymore, so they ended up calling their HIV nurse” (7 years, registered nurse, large centre).

The centrality of trust was linked to the societal burden of HIV, i.e., problems with disclosure, the intimate nature of HIV and its links with sexuality, morality and sexual health: “for some, it is so sensitive that nobody knows about [their HIV]. At that moment, I am the only one with whom they can discuss their HIV. Nobody else knows, not their family, nobody” (9 years, registered nurse, small centre). Trust and confidence were significant not only for the physical well-being of the patient but also crucial in dealing with psychosocial issues: “we also deal with issues that are completely unrelated from their HIV infection, but it indicates how deeply connected our job is to psychosocial care” (7 years, registered nurse, large centre).

Nowadays, with effective therapy, patients are living longer and remain in care longer. Several nurses stressed the longevity of their relationship as meaningful: “yes, you know people for a long time. You also see a lot of changes [...]. This is of course the luxury of knowing people long term” (16 years, registered nurse, large centre). In effect, the quality of this relationship was cherished and celebrated by nurses. Discussing the fact that a patient who moved to a different town preferred to remain in care in his ‘old’ treatment centre, one nurse reflected: “That is beautiful, at least for me as a nurse” (22 years, registered nurse, medium centre). For some nurses, this relationship even became reciprocal. As an example, one nurse who used to work in a different context, claims this was eye-opening: “before I didn't even share where I lived; now I talk about my vacations, my children. Yes, that is a major difference” (6 years, registered nurse, medium centre). Connected to this sense of trust was a more nurturing or caring aspect: “the fact that [consultations take place] at the hospital makes us feel very safe for the patient. Also, I am there [as someone] familiar to the patient” (my emphasis) (15 years, nurse practitioner, large centre).

This close and intimate connection with the patients also had another side to it. Because nurses are well known to ask additional questions and to explore themes that are outside the immediate scope of treatment, some patients actively avoided consultations: “Then, they can also try to avoid us, exactly because we can address every topic, also substance use. For some, this is rather difficult and that means they will avoid us” (9 years, registered nurse, small centre).

5.2.4 | Increasing complexity of HIV care

In the professional imagination among nurses, an important distinction is maintained between nurse practitioners and registered nurses based on the responsibilities they have. From the perspective of nurse practitioners: “A [registered] nurse only addresses the psychosocial, but I am also responsible for your bone problems, your cardiovascular, your HIV, your lab results, the letters to the GP, plus

also your acute complaints, the psychosocial, stigma experience, sexuality, adherence" (20 years, nurse practitioner, large centre).

Nurses in different treatment centres identified how their tasks and job descriptions have become increasingly complex and that the way care is provided has evolved accordingly. Complexity here refers to their function within the treatment team rather than to the purely medical or clinical treatment of HIV. Contemporary care, for nurses, entails the consideration of both physical and mental well-being of patients. Nurses also considered themselves a first point of entry into the health-care system. They stress that providing holistic care is synonymous with providing good care: "This person is there with all his inabilities, vulnerabilities, and you have to provide the best care possible. You need to consider who that person is, what this person needs to come to grips with the disease and all its effects, emotionally, sexually. Also, [...] the experience of stigma, how to cope with that. Yes, that is very much the task of the nurse" (22 years, registered nurse, medium centre).

The number of referrals is a key indication of this increased complexity. One nurse described her position as a "spider in the web" who needs to "maintain short lines with other health care services" (9 years, registered nurse, small centre). Contemporary HIV care is about identifying issues, both clinical, mental and societal, and referring to the right services at the right time. Nurses saw themselves as gatekeepers towards other health care providers in the treatment team and the health system as a whole.

Finding responses to the complexity of nurses' tasks often occurs in an increasingly difficult institutional context. This concerns core nursing staff for the HIV clinic, "before, there were five of us but that has been scaled down, now there are two of us and hopefully soon we will be three. But the two of us, we also don't work full time" (4 years, nurse practitioner in training, large centre). This also concerns the availability of allied professionals who support nurses like social workers or psychologists: "we think it is a disadvantage, but due to financial constraints, our psychologist only has limited allocated time. We had to agree that the appointments we do make, can only be directly HIV related" (19 years, registered nurse, large centre).

Contrary to this increasing complexity with ever more referrals, some nurses indicated that this has a negative influence on their relationship with their patients. They had a hard time letting their patients go: "the more people you put between my patients and me, the less I can report. And yes, I find that undesirable" (30 years, nurse practitioner, large centre). Still, a holistic approach to care was considered primarily a nurse's task. Compared to the tasks of the medical specialist, one nurse commented: "there are doctors who discuss psychosocial problems, and this is important. Still, I have studied nursing for eight years and it is not up to the doctor to discuss adherence, sexuality or stigma, these are topics that belong to the nurse" (20 years, nurse practitioner, large centre).

5.2.5 | Perceptions of changes in HIV care

Nurses' awareness of the complexity of contemporary HIV care was linked to an explicit reflexivity about past changes. During

interviews, there was a lot of mention of these changes, moving from a rapidly progressive infection to a manageable chronic condition resulting from medical advancements but also questions were raised about possible future directions for HIV care. Those nurses who experienced the early days of the epidemic were quick to draw comparisons with the palliative care they provided, something that is passed on in the collective imagination of the profession to younger generations of nurses: "People used to die. I have witnessed this in the clinic. They needed really intense care. I know from colleagues who also experienced intense circumstances that you guided people until they died with as little discomfort as possible. That has changed obviously, fortunately due to the success of the treatment, so that people [with HIV] had to reorient their lives with new perspectives" (20 years, registered nurse, large centre).

In terms of their own practice, nurses saw a significant shift in responsibilities since the development of effective treatment, from the medical to the social and to discussing comorbidities: "Before, initiating treatment was a major issue and [getting] blood results, those kinds of things. Now lifestyle, prevention of [mental] health problems are becoming much more important. Yes, ageing with HIV gets more attention. In the past, hearing your diagnosis and the moment you started with medication were two different moments; that is now one appointment" (16 years, registered nurse, large centre).

In addition to determining time to start antiretroviral treatment, the discussion of side effects was now considered less important: "what has changed is the focus on medication. The side effects that people experienced back in 2007 were substantial. [...] [T]hat has disappeared completely. I ask about it, but it is not really a topic of conversations. [...] The U=U message, that is now incredibly important. That has changed my job considerably" (15 years, nurse practitioner, large centre). New tools and new developments in medication continue to change practices and work routines: "there are injectables now, people have questions about that: how is the research done, how many people are using them?" (6 years, registered nurse, medium centre). But not all changes were welcomed and desirable as they might impede on the authenticity of the relationship with the patients: "ah, yes, these questionnaire-based conversations, I don't feel for it at all. Really, I find it difficult to let go of looking into people's eyes and saying, 'tell me, how did that story with your mother end?'" (30 years, nurse practitioner, large centre).

Given the changes that occurred, nurses held different views about the potential shift from specialists and their support teams, including nurses, to GPs and the most appropriate location of HIV care. On the one hand there were those who argued that "there are many GPs who have the experience and scientific background. They have had HIV patients in care for 30 years. There are famous Amsterdam-based doctors who have experience and there is nothing wrong with that" (20 years, registered nurse, large centre). On the other side of the spectrum, nurses identified limits to the GPs' ability to take over specialist care: "No, there are enough people who don't want to go to their GP, but they want to come to us with all of their problems. Of course, you have to set boundaries, but it is an

indication that they want a fixed point of contact" (8 years, nurse practitioner, large centre).

5.2.6 | Particularities of HIV in society and in care

By highlighting their everyday experiences, nurses mentioned the continuing particularity of HIV and, subsequently, HIV care. As one nurse summarized it: "HIV is no longer the problem; everything else is" (20 years, registered nurse, large centre). Beyond providing individual health care and concerns about the physical well-being of their patients, nurses articulated the public health concerns linked to providing care: "It has to do with social responsibility because it concerns a communicable disease. So, you have to do more than for somebody with diabetes or asthma. I think it just grew out of the history [of HIV]" (14 years, nurse practitioner, large centre). Ensuring that patients remain in care and adherent to their treatment was seen as a key responsibility among nurses. In addition, nurses acknowledged that patients more often struggle with non-medical concerns: "Look, HIV as a disease, there are many diseases more difficult to live with. Imagine you have diabetes and having to inject insulin, that is much more complex. [...] If HIV is a secret, then the HIV becomes much more severe" (28 years, nurse practitioner, large centre).

6 | DISCUSSION

In this qualitative study, we set out to understand the experiences of HIV nurses as they provide care in an era of biomedical optimism and changes in the organization of care, but also considerable burden experienced by PWH. We have presented six key themes that HIV nurses articulate in their experience of providing care for PWH: three relational themes dealing with the everyday experiences of nurses and three conceptual themes dealing with perceptions of care. Relationally, nurses identify patient populations that require more attention and a different level of concern, both for their own individual health and continuing public health risks. They are flexible in the way they organize and structure their consultations to accommodate for patient needs and concerns and experience a unique relationship with their patients based on trust and the intimate nature of HIV. Conceptually, nurses identify their tasks are becoming increasingly complex and their approach to care to be comprehensive and holistic. There is also an explicit awareness of changes in health care practices over time and possible implications about the organization of care for the future. Compared to other chronic conditions, HIV continues to occupy a particular position among nurses that requires a specific approach.

The nurses' experiences and practices align well with other studies on the contemporary role of nurses in HIV care. A scoping review on the contribution of nurses to HIV care has highlighted the complexity of nurses' tasks and emphasizes the combination of fulfilling both clinical and non-clinical tasks, of providing

non-medical support to ensure adherence and to fulfil an outreach role towards a community setting (Tunnicliff et al., 2013). Chu and Selwyn (2011), in a study on recent changes in HIV care in the US, noticed that providing chronic care actually involved taking on primary care tasks, a message that is echoed by the nurses who participated in our study. In line with chronic care models, both for HIV and other (non-communicable) diseases, a higher workload is attributed to the fact that patients, with the current treatment options, remain in care for much longer (Dave, 2004). In addition, political and policy-related decisions concerning spiralling health care costs as patient-centred chronic care is provided lead to increasing responsibilities with limited core and support staff (Piercy et al., 2018; Temmink et al., 2000).

It is well documented that the population of PWH is ageing. This brings new concerns about chronic comorbidities and other non-HIV related medical conditions, which results in challenges to delivering adequate care over time (Kiplagat et al., 2022). Although the 24 HIV treatment centres in the Netherlands are not nurse-led clinics, the actual tasks that nurses perform and the experiences of their institutional context resembles nurse-led institutions to a certain extent. The nurses' experiences suggest the relevance of rethinking the role of nursing in providing patient-centred chronic care from a health systems perspective, like others have done for nursing in general (Kitson et al., 2013) and for HIV specifically (Piercy et al., 2017). Also relevant from a health systems perspective are debates about the connection between patient-centred care and the need for differentiated service delivery for PWH (Roy et al., 2019). As demonstrated by others in this regard, nurses are able to identify the needs of different target groups within the patient population (Tunnicliff et al., 2013). They can effectively adjust their services to accommodate patient needs beyond routine consultations, to ensure adherence and retention in care since the burden of living with HIV experienced by these patients is perceived to be much greater than for PWH.

HIV as a chronic condition, and framed within chronic care models, implies normalization (McGrath et al., 2014). Still, our findings suggest that HIV exceptionalism is being replicated in the context of care. Social scientists have addressed the reproduction of HIV exceptionalism despite clinical and biomedical advancements (e.g. Benton, 2015; Moyer & Hardon, 2014). They warn against simplified narratives of normalization and even challenge chronic care paradigms because these tend to erase the complexity of PWH in low-resource settings where basic care or access to ART is not readily available or where ageing with HIV is not self-evident (McGrath et al., 2014). The notion that HIV exceptionalism exists or is reproduced also among health care professionals is not new. So far, most research on this topic has been conducted on attitudes among non-HIV nurses, where case studies explore knowledge about HIV and the way this impacts stigma and prejudice as it influences the treatment of patients (Frain, 2017; Petroll et al., 2008). Similar research has been conducted among medical doctors who also lack knowledge and awareness on the topic, which results in negative attitudes towards people living with HIV (Stutterheim et al., 2014). In fact, studies stress knowledge gaps and outdated

representations of HIV among specialized doctors which suggests the reproduction of HIV as an extraordinary illness even in HIV clinics (Persson et al., 2014). Our findings suggest that, in addition to knowledge gaps, awareness and attitudes, *the interactions with patients* and a sense of nurture that results from this interaction further reproduce the exceptional status of HIV, not insignificantly in light of the fear of losing patients from care. An older generation of nurses indicated that their earlier experiences continue to inform their present-day attitudes. The experiences from the era without effective treatment are also well recognized by a new generation of nurses as they are confronted with long-term survivors and narratives of older colleagues. This is something that is hinted at in a UK study on the culture of care among HIV nurses (Hodgson, 2006).

In the experiences of the nurses, empathy proves to be a central concern that guides the everyday interactions and practice during consultations. On the one hand, empathy is a key quality of long-term chronic care, as others have illustrated, both for HIV and nursing in general (Cunningham et al., 2007; Dawson-Rose et al., 2016; Feo et al., 2017; Graham et al., 2010). In line with patient-centred care practices (Bahlman-van Ooijen et al., 2022; Kitson et al., 2013), empathy is translated in organizational flexibility based on patient needs. Nurses take extra time for initial consultations, make room for additional appointments where needed, answer direct questions from patients or allow partners to come along for consultations. In their interaction during a consultation, nurses emphasize how they can build genuine connections with patients and to develop long-term, in-depth and trust-based relationships. Nurses aim to provide low-threshold accessibility, recognizing the needs of patients.

On the other hand, trust and empathy seem to be instrumental in the reproduction of HIV exceptionalism as they are linked to the public health concern that is part of HIV care. In making sure patients are engaged and remain in care, nurses emphasize the need to empathize to ensure adherence. Discourse on adherence and, prior to that, compliance, has been linked to the increasing medicalization of care (Mykhalovskiy et al., 2004). Compliance, even more than adherence, is linked to the predominant focus on surveillance and control in care (Burchell et al., 1991) and to the management and governance of bodies, which has been described as the antipode of patient-centred care (Gagnon et al., 2013). Still, discourse on adherence has received criticism because it *excludes* the patient experience. Rather than the clinical health of individual PWH, nurses indicate the importance of the public health risks when PWH are disengaged from routine care. This biomedical focus is also reflected in the “end of AIDS” discourse, which is based on the management of the continuum of care that tracks how many people are aware of their diagnosis, are in care, are on treatment and are virally suppressed. This gold standard of prevention relies on the effective control of the HIV viral load of PWH and therefore ensuring adherence (Sangaramoorthy, 2018). In effect, the advent of effective treatment meant that medical adherence became a prominent feature of HIV care (Nguyen et al., 2011). People on treatment can no longer pass on the

virus (U=U) (Rodger et al., 2019). So, despite the shifting focus to chronic patient-centred care, the remnants from alternative systems of care that prefer surveillance and control linger on in everyday practice and concern, a dynamic that is also linked to the reproduction of HIV exceptionalism (Moyer, 2015).

6.1 | Strengths and limitations of the work

We were successful at including a diverse sample of nurses working in treatment centres throughout the country in our study. Our focus on experience facilitated study participants to introduce and discuss themes that are relevant to their own experience rather than themes introduced by the researchers. Our research focused exclusively on the experiences of nurses. A more comprehensive view which includes that of medical specialists and patients would provide a more complete picture of how chronic care is experienced by all relevant stakeholders involved. This is significant given the perceptions about specific patient populations like MSM or people with a migration background. Even though our study is framed against the systemic background of chronic care models, it is not a direct evaluation of these models for the case of HIV.

6.2 | Recommendations for further research

Our findings suggest that further research should be conducted on the patients' experiences of contemporary HIV care and of their expectations of their health care provider to assess not only the quality of care but also the social construction of representations of health and illness.

Given the centrality of affect and trust among nurses, we recommend more fundamental research to better understand the relationship between nurses and patients in order to form conceptual and theoretical models.

6.3 | Implications for policy and practice

In light of ongoing debates about the organization of care for PWH, our findings provide a solid contextual background of representations and practices among nurses. These findings can inform formal evaluations of the role of nurses in HIV care and discussions about the reorganization of care in cooperation with primary care, task shifting towards community- or nurse-led clinics or towards further differentiated service delivery for PWH.

7 | CONCLUSION

Our qualitative study among HIV nurses in the Netherlands maps out their experiences with providing long-term chronic care. Biomedical advancements have transformed HIV into a manageable,

chronic disease. This has inspired discourse on normalization and implies changes in care practices towards more patient-centred care. Despite this biomedical optimism, our findings show a continued entanglement between clinical and psycho-social complications relating to HIV. The nurses' tasks are growing increasingly complex, and their work is defined by a holistic and interdisciplinary approach. Based on the relationship nurses have with their patients, and their understanding of the latter's experiences living with HIV, and continued public health concerns, a sense of HIV exceptionalism is being reproduced in formal care. This ambivalence of the nurses' experiences and practices is important in light of ongoing debates about the organization of care for PWH and the proposed central role of nurses in chronic care.

AUTHOR CONTRIBUTIONS

Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data: Maarten Bedert, Kevin Moody, Pythia Nieuwkerk, Marc van der Valk. Involved in drafting the manuscript or revising it critically for important intellectual content: Maarten Bedert, Kevin Moody, Pythia Nieuwkerk, Natasja van Holten, John de Wit, Marc van der Valk. Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: Maarten Bedert, Kevin Moody, Pythia Nieuwkerk, Natasja van Holten, John de Wit, Marc van der Valk.

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MvdV has received unrestricted research grants and fees for participation in advisory boards from gilead, MSD and Viiv all paid to his institution. KM has received fees for educational activities from Springer Media and Gilead Sciences. Other authors have no reported conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Maarten Bedert  <https://orcid.org/0000-0002-5899-0663>

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